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Reframing neonatal care from an empathic care perspective

Abstract

Neonates are subjects of rights and, when they become patients, they should be valued as patients. Clinical empathy refers to the way health professionals empathize with patients and is an essential component of patient-centered care. Considering the paucity of studies regarding empathy in neonatal care, this theoretical article aimed to provoke a discussion about this issue and suggest a reframing of neonatal clinical practices. We emphasize why we should empathize with the neonate, considering the bioethical and quality of care aspects, the results of care, and the new reality of post-pandemic relationships. On a practical basis, we report how we can empathize with the neonate, reinforcing the need to see him as the patient, protect his best interests, the role of communication in healthcare, and the need to maintain the other-orientated perspective.

Keywords: clinical empathy, empathic concern, neonate, patient-centered care

Volume 9 Issue 3 - 2023

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Received: August 15, 2023 | **Published:** August 31, 2023

Introduction

The neonatal period comprises the first 28 days of life, and this is a critical period for human development and survival, as many infant deaths occur during this period. We must recognize that the neonate is a subject of rights[1] and quality of care during the neonatal period is a determinant of survival.[2] Although technological development in health care brought advances, emotional detachment, and excessive objectivity left no or a minimum space for the human dimensions of illness, encompassing the psychological, social, and moral dimensions of suffering.[3] These technological advances have resulted in a reduction in neonatal mortality during the last decades, but quality of life remains a great challenge.[4] Surprisingly, among the suggestions of mothers on how to improve the quality of maternal and neonate hospital care it was observed that, among the top suggestions included, were the need to improve staff professionalism, empathy, and kindness.[5] Neonates are vulnerable as they are non-verbal, and it is difficult to understand their preferences and experiences, as they communicate through gestures. It is important to view the neonate as a patient, and in this situation, an additional vulnerability exists. Only by the interpretation of the neonate's communication, we can establish effective clinical reasoning.[6]

Empathy is an umbrella term that describes how people respond to others' emotions, necessities, and perspectives. From an ethical approach, clinical empathy, which expresses the way health professionals empathize with patients, could be understood as the human purpose of medicine, and comprises a cognitive and an emotional component.[7] In the neonatal care scenario, health professionals usually try to empathize with parents and fulfill their needs and expectations, but it does not apply to the patient, the neonate. Over the years, different models of care have been suggested, being patient and family-centered care the last one advocated by the American Society of Pediatrics.[8] This model understands that the child's family is his primary source of strength and support. Patient-centered care models, on the other hand, consider the patient's perspectives, preferences, and knowledge of the clinical decision, with the active participation of family and parents, but are focused and aimed at the patient. These models are improbable to occur if empathy is not established[9] and are unlikely to occur in neonatal care if the neonate is not valued as the patient. Again, it is important to reaffirm that when we suggest patient-centered care as a model of care for the neonate, we do not advocate for family detachment from neonatal care (Figure 1). Instead, we provoke health professionals and parents to beware of the neonate at first, as he suffers singularly. Considering the paucity of studies regarding empathy in neonatal care, this theoretical article aimed to raise a discussion about empathy in neonatal healthcare and suggest a reframing of clinical practices. We adopt the research of Howick, Jeffrey, Hojat, and Zaki[10–16] on clinical empathy. The personal experiences of the authors concerning neonatal healthcare will pave the discussion. This article is structured in two parts: why we should empathize with neonates and how we can do it.

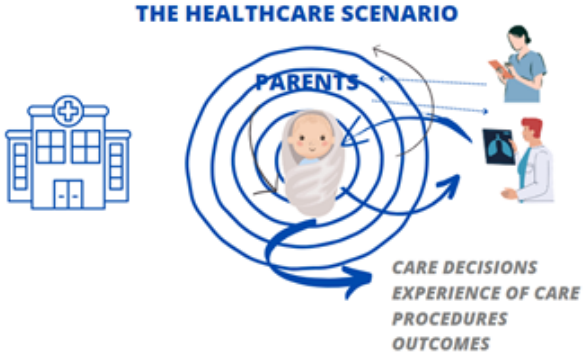

Figure 1 Model of patient-centered care where the neonate is valued as the patient, by health professionals and their parents, and decisions and procedures result from this interaction (this figure was made by the authors).

Clinical empathy: why we should empathize with neonates

There are many arguments to justify empathy in the care of neonates. Firstly, it is an evidence-based intervention. Albuquerque[17,18]

pointed out that the current context of care that violates patients' rights, objectifies, and reduces the patient to a disease, claims for meaningful care, to change this reality. Also, she states that bioethics in healthcare is based on clinical empathy and its developments in the various components of care quality, such as communication and patient centrality. This reflection should include the neonatal scenario. The neonate is vulnerable and worthy of care, as we pointed out. His innate social dependency on others puts him at risk of perishing. As he is non-verbal, he communicates through gestures and behaviors. To understand this dependence and why we should protect neonates, health professionals need to shift the way they perceive neonates and respond to them in an ethical manner, considering that empathic care is morally justified and matches dignity and patients' rights. Pols et al.[19] conceptualized dignity as a mirrored experience that arose when health professionals actively engaged with their patients, reflecting the need to understand healthcare relationships as engagements that are actively constructed.

In the clinical scenario, for example, pain in the neonate is under-recognized and under-managed. Ilhan et al.[20] suggested that pain management in the neonate is influenced by both a reflective (taking the perspective of another) and an affective empathy (fell what the other feels) and so, health professionals should collectively cultivate empathy, especially in the neonatal intensive care unit. Guarantee of pain prevention and reduction is a guarantee of dignity in healthcare, as no one should feel pain if this can be alleviated. Changing professional practices requires a shift that includes ethical issues, considering, for example, standards for decision-making, particularly the best interests of the neonate, which balances risks and benefits and involves patients' rights and quality of life. On the quality-of-care prism, some trials have been showing that empathy can improve it.[21] Empathy is cost-effective and tends to forward more accurate and rapid diagnosis. Also, it increases patients' satisfaction.[10] Coming back to the example of pain in the neonate when a health professional empathizes with the patient, he "*sees the patient's pain with patient's eyes*" and this can help the suspicion of threatening conditions such as necrotizing enterocolitis, a disease that causes abdominal pain in the neonate and can cause death. Compassionately, the health professional will be involved in relieving the patient's pain, instead of thinking "*Oh, this is a crybaby, he is crying all the time*", which would create a tag for the neonate as a crying baby and delay diagnosis. Pain is probably the best example of a suffering and bad condition that results in a bad quality of life, and empathic care can reduce it.[20]

Interestingly, empathy is a dynamic process where patients and health professionals learn more about each other over time.[12] Health professionals also benefit from empathic care, increasing their well-being and satisfaction with their work, reducing burnout and medico-legal issues.[11] Last, but not the less important, it is reasonable to think that, in the post-COVID-19 pandemic world, as interpersonal relationships were affected, there is a need to reestablish human relationships. Health professionals tended to decrease their level of empathy to protect themselves from suffering, and this occurred naturally. It has been suggested that the pandemic influenced healthcare professionals' relationships with patients. Saladino et al.[22] discussed the effects of the pandemic on empathy, and they pointed out that difficulties in managing patients' emotions may have caused suffering as high as that caused by COVID-19, possibly leading to detachment.

Clinical empathy: how we can empathize with neonates

First, we would like to ask some questions for all health professionals who work with neonates and are reading this article. Daily, how often do you include the neonate in the clinical decisions regarding his health? How often do you consider his best interests for the overall decisions? How often do you dedicate time and attention to his emotions?

Zaki reported his and his wife's experience with his son Alma, who was admitted to a neonatal intensive care unit (NICU). Some months after her discharge, he returned to the NICU and observed health professionals, patients, and their families. This observational work is reported in his book, and I want to share a case he commented on. It was the case of a critically ill preterm neonate who developed necrotizing enterocolitis and had an intracranial hemorrhage, worsening his prognosis. His parents had difficulty understanding the whole situation, and the final decision was to move forward with the surgery. When the surgeon opened the neonate's abdomen, he saw that the entire intestine had died. I do not aim to criticize the decision that was taken, to move forward with the surgery, but why do we take heroic lifesaving measures even when they are likely to fail?[15,16] Do we usually respect the best interests of the neonate? Maybe this case reflects that, at that moment, with the disease progression, suffering relief would have been the best choice, instead of a surgical intervention. This case brings up the interconnection between empathy, communication, and decision-making. The neonate's parents did not understand completely what was going on and ceded the decision to a pediatrician. It is not possible to empathize with the patient without effective and empathic communication. Breaking bad news is supported by protocols of communication that include empathy, such as the SPIKES protocol,[23] but we want to reinforce that all communication through healthcare should be improved. So, to provide empathic care, we must communicate empathically. One strategy to organize this communication in steps is to first name the emotion involved, understand, respect, support, and explore, elements of the N-U-R-S-E technique, and these abilities, can be improved.[24] The first thing to do is to N-name the emotion involved and then, U-understand what's going on. It is well known that communication can be effectively learned, there are many models proposed to structure communication in the clinical scenario, and most of them, if not all, include empathy in their approach.[25] It is not reasonable to assume that all health professionals know how to communicate, without having been trained in it. Yet neonates can feel emotions, such as well-being, sadness, happiness, and fear, we usually do not value this. For a long time, they were considered as emotionally limited and merely receptors of external stimuli. Differently, we currently know that they are able to interpret external stimuli and most of all, they build the perceptions of everything that reaches them since birth, attributing value and meaning. Actually, they decodify the world where they live.[6]

As health professionals, medical teachers in Pediatrics, and researchers about empathy, we engage in discussions about difficulties that patients have to follow medical recommendations, causes of hospital evasion, misunderstandings between parents and health professionals, and so on. And it is incredible that in many of these discussions, the child is not the center of interest. So, the first thing we should do is put the neonate in the center of care and protect his best interests. Then, we should recognize that there might be a gap in the empathic care of neonates, and this violates their patients' rights, as they are worthy of this, and their interests should always supersede any other interests. If we neglect this point, all the other reflections turn to nonsense, as we do not have a real problem to face. Also, we should be willing to empathize, otherwise, this would not happen.[12] This does not preclude the implementation of guidelines, on the contrary, guidelines and empathy should complement each

other. Howick discussed empathy in healthcare, and he pointed out that excessive guidelines and excessive paperwork are barriers to its implementation. He stated that guidelines are essential for good patient care but should be embedded in a culture of empathy.[10] It is something like guidelines stating what we should do and empathy care, stating how we should do it. From a personal point of view, *empathy is the magic that enables guidelines to jump from papers and computers and reach the patient*.

Health professionals have the intention to empathize in the neonatal care scenario, but they have some difficulties and need support. We are applying the Jefferson Scale of Empathy (JSE), the version for Health professionals (JSE-HP),[14] and we can see that they have difficulty recognizing and validating neonates' feelings and emotions. The JSE-HP is the most frequently researched and used instrument to measure clinical empathy in healthcare professionals.[14] The components of JSE-HP relate to perspective-taking, compassionate care, and walking in the patient's shoes, in this order of relevance. We report the scale, as it helps in the understanding of how we can practice empathy. These dimensions evaluate our ability to experience sharing (emotional empathy), caring (motivational empathy), and thinking about, the last one the cognitive piece of empathy.[15] Let's examine again, an experience of pain during a procedure in the neonate. As health professionals, if we understand his feelings, have insight into his mind, try to imagine what he thinks about it, and are influenced by his feelings, then we choose the best moment to do a procedure (considering the best for the neonate), and we prepare the neonate not to feel pain or minimize it at most (Figure 2). This ability to empathize involves the motivation of prosocial and caregiving behaviors paired with a drive towards the patient's welfare.[26] Empathy is positively correlated with prosocial behaviors,[27] and this is the glue that enables all kinds of relationships. So why we still collect blood samples for exams for example, without any pain relief, has no explanation and this should change quickly.

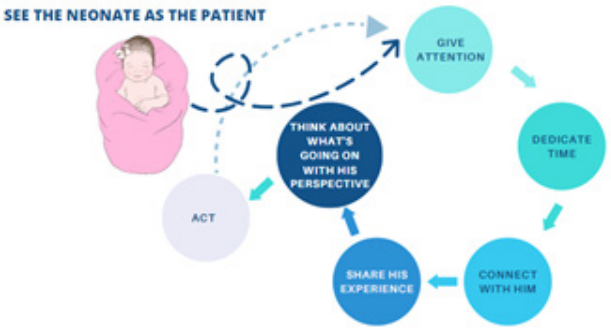

Figure 2 A suggestion of the steps to empathize with the neonate (this figure was made by the authors).

Some strategies have been implemented to improve neonatal care. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP), a milestone in the care of neonates, provides individualized neonatal-focused and family-centered care in the NICU, especially for preterm neonates. It was idealized for high-risk neonates, as they are so vulnerable to neurodevelopmental impairments, and has been essentially a nursing program for neonatal care. Though NIDCAP results in better neurodevelopmental outcomes, and its results have been studied for at least two decades, it was not implemented worldwide, due to obstacles to its implementation.[28] In fact, it is difficult to reconstruct the art of care. Specially in the NICU scenario, as the intensity of care increases, empathy needs to be rescued, justifying the focus on the patient. But why do we exclude the other neonates who are in the rooming-in, for empathic care? And why this is not patient-centered care? We know that interventions on the family result positively in the neonate, increase family's satisfaction and enable parental attachment, but we want to reframe this care to a patient-centered one, provided to all levels of care and with the participation of all health professionals, in a conception of a real culture of empathy in the neonatal care.

Finally, it is important to emphasize that the neonate-orientated perspective, instead of our perspective, prevents us from losing sight of the patient as another person and protects us from compassion fatigue and personal distress.[12] Our knowledge and priorities should not prevail over someone else's. So, clinical empathy is not to put myself in the other's place, as many people think it is. Instead, it is a bioethical-oriented way to care for the patient by understanding his perspectives and feelings, acting according to this understanding, helping the patient, and recognizing him with dignity and respectfully.[10,17]

Final considerations

Empathic care results in several benefits to patients, their families, and health professionals, improve the quality of care and is more respectful to neonates. Although neonatal care has evolved, aiming to improve neonatal outcomes, clinical empathy has been difficult to be understood in the neonatal scenario. Patient-centered care is a challenge for the neonate, as he is rarely seen as the patient. To change this scenario, we suggest that firstly, this gap must be recognized, and then, the neonate should be put in the center of care, communication abilities should be improved, we should give attention, dedicate time, think about what is going on with the neonate's perspectives and base our daily actions on these steps. A reframing of the traditional model of neonatal care is urgent, and this could be strengthened by an empathy culture in healthcare.

Acknowledgments

None.

Conflicts of interest

The authors declare that there are no conflicts of interest.

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Citation: Valete COS, Albuquerque A, Ferreira EAL, et al. Reframing neonatal care from an empathic care perspective. *Nurse Care Open Acces J*. 2023;9(3):117–120. DOI: 10.15406/ncoaj.2023.09.00270